

PSJ3
Exhibit 48A



AMERICAN PAIN FOUNDATION CORPORATE ROUNDTABLE



PARTNERSHIPS PROMOTING INFORMATION, SUPPORT,
AND ADVOCACY FOR PEOPLE AFFECTED BY PAIN

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APF Industry Roundtable 2003

industry = problem solvers

Lennie = new role includes corporate relations

Will - spectrum - VT - youths/troubled

Will

intentional connection to industry - common mission

getting better connected to people served by APF
↳ listening better

- 3 levels of advocacy:

(1) consumer mobilization strategy

get voices of people in pain/caretakers together to get msg out to those who can Δ laws, policies, other targets

(2) info & support org but still hitting wall

\therefore need ~~more~~ personal advocate strategy

ombudsman in local community

from individ up

(3) community advocacy - getting them to

educate people in own community

eg, rotaries, faith-based, etc.

also to stimulate investment in APF

Natl Survey - a lot of misinformation exists

surveys promises info to clarify situation

APF BACKGROUND - WILL

~ 75M w/pain (various #'s exist) - individuals -

no profile # all walks

what we do is listen

knowledge exists - not being used

1997 APF founded - largest consumer org in pain

who serve - people w/pain

↓
individuals

- caregivers, family, friends
- healthcare professionals

How work → listen / target goals - response / results

↓
improved pol,
policies, etc →
measurable results

[Natl Pain Survey part of getting results - how to measure]

need to work collaboratively ^{including} ~~not~~ industry

Yvette Colon - Dir of Educ & Internet Services

Toll free info line 1888 615 PAIN

1st patients, some caregivers, ↑ ^{healthcare} providers

provide info - direct to resources

info @ painfoundation.org [similar info]

also answer govt re: clinical concerns

how to talk to clinicians / barriers

Yvette or Mike → not med advice

↓
other

↓
med nursing

MICHELLE BROWN - ADVISOR FOR PAIN MGMT
after Pam Bennett went to Purdue
was clin nurse in western Maryland

Publications

did Bill of Rights before came (now spanish,
(antonese)

Pain guides → reading this could ease your pain
"how can i find help" - key question - finding
help

targeting clinician - not necessarily pain spec
how to ask right questions / useful tips
pain notebook - plot pain experience

↓ 2 pieces
hope/will lead to ~~can't~~ right dialogue

Marty - hope will consider affect on function
? - how distribute

Lenny - pain spec & one 1st as target

Pam - at medical mtgs - would you use

Marty - how can you (industry) help us w/marketing

Jim - don't ask re: pain - opening can of worms -
too much time

must deal w/attitude

pain notebooks in waiting rooms - empower pts
to bring up

Mike - getting input from pts to see if useful
can network w/ them to get word out

Target - nurse/MD advisors

Michael Young - need to find way to know who
is using
business reply cards vs. office

Marsha - not only pherm - also a NP/PAs
Lennie
going to nurses

Nancy/
Elan - taking person successful to be "mentor"
to others to tell how the story succumtly

Lennie - purpose to diary to teach communica
tips to have person on phone / not just reading

Don
- cooperation? How will AIF interact w/ other
orgs? overlap exists

Will - mobiliz. - partnerships w/ grassroots
must be strategic in how to work w/
others specific issues

Yvette

www.painfoundation.org

visits 51,000/month

- in the news

- Voices of People with Pain

- Pubs - downloadable

Painaid.painfoundation.org

online support group

led by 25 Linda Spaid staff - rest volunteers

comraderie among moderators

can get support w/out posting

10 msg boards

Technology-Based Projects

eg, consumer CD - CAPain

neuropathic pain

back pain

others have
come to US
requesting

e-newsletter - APF Pain Monitor

→ also live chats ~ 10/week

Ask-the-Expert w/ 10 licensed prof

massage, nutrition, podiatrist

Next steps

reorg website

underserved incl child & youth

~~data~~ point & end of life

- articles

- facilitated online discussion forum

w/ articles

everything on web also will be made in print

Personal advocacy - train personal advocates/ navigators

training/outreach / ^{eventually} online searchable database

* children & youth - for them / for parents
↑
none exists now

Psm - diversity? other languages

Yvette - need to find bilingual advisors

- lots of hit for Spanish materials

- limited what we can do internally

there are services that translate internet
investigating

Q - David -

What are most common questions?

Yvette *
A - clin research/trials - working on new section
soon

3 most accessed

{ pain Action guide
in the news
voices

Communication - Lennie

Pain Community News - 1 topic

eg, opioids

alternative med

Pain Monitor News - Carol (Jan 2003)

e newsletter

vehicle that people took ownership of
have section directing people to resources in
spanish (Yvette)

6,000 database

also 8-10 orgs give to their mbrs

print & e newsletter archived on website

clinical trials → new initiative

Jim - many pt w/ diff conditions need trials
disconnect w/ industry & ability to accrue
help & industry link to pt

[eg, focus group for notebook - very fast response]
an e-newsletter

Lennie - e-newsletter way to get info out fast

Lennie - media

balance - undertreated pt / worse than diversion

POWER OVER PAIN

was before called Stop Pain Now

initiated w/ Pam when @APF

w/ AACPI w/ partic of ACS, ASPMH

MA, FL, LA

launched w/ state-wide survey

similar results to MD except FL (higher)

grassroots

goal - ↑ awareness

next year - 3 more states + continued support

Pain - now in 3 states more \oplus media than \ominus

(did during sept - Pain Awareness Month)

Pain Inst working w/ reg div of AGS
 \Rightarrow many nurses

now doing local educ, eg, libraries, rotaries, etc ^{chapel}

next steps

community advocates - Adrian Braun 1st

ADVOCACY - WILL

will be filling advocate position (legislative)

also a mobilizer - online action center eg,
explicit things can do

looking @ models of mobilization that do it well

Paro-Medtronic
[when hiring @ turn of year]

Lennie - Pain Survey

w/ Cleveland

have some pills - some challenging # \therefore need study

eg,
extent/magnitude of problems, causes, effectiveness
of treatment

1st step to push research

* APF plans to make database (which will be cleaned) available to funders

review data

create report card

prep 1-7

data collect 7-11 mo

prepare data 12-13 mo

anal mos 14-16

final mos 17-18

18 mos
w/out pretesting

Questionnaire Design

- screener < pain in last 3 mos inc successful managed

- Fundic Site ~~(which)~~

then where

severity
interference

neuropath

pain specific
treatments

group 1 questions in pain

demog

phys funct

Mental health funct

work status

gen with comorbid

health care access/utilz
barriers

SF 36

Bill Frey - Westat

mbr of scientific cmte of APF (w/Cleveland)

Design: 5 objectives

- prevalence
- methods used to treat & manage pain
- barriers
- financial costs
- impact on QOL

non-institut US adult pop / random digital

computer aided telephone interview (w/Spanish)

reverse directory match to addresses to ↑ participants

screen for # 18+ - sample only 1 adults

10,000 completed interviewed to get smallest group

expect 4,500 - 5,500 w/pain

150-300 in smallest pain group (neuropathic)

conduct cognitive interview of questionnaire
pre-test quest.

} already
have 1st
draft -
being
revised

once done, translate to Spanish

computerize - training

conduct interviews

convert refusals

monitor & supervise interviewers

group 2 - subset of no pain

Marsha
~~Marsha~~ - incentives?
none give

~~with~~ ~~the~~ AFF has asked to add follow up

Marsha
why focus on neurop.

↓ sample size due to cost
think can capture all groups

Tom - will results be published in journal - yes
can we get copy of slides - yes

Jim - NEJM or JAMA Cleeland's target
may then be more mining

NIH
Bill Frey - ~~not~~ interested - may do symposium
NIH-wide meeting envisioned (Oct 2018)
no financial involvement from NIH - timing
[Loser involved in defining neuropathic pain]

headache pain ~~not~~ included but separate
[Don created w/ impetus by Campbell]
↓
celegene

Don - stated diagnosis may not match

Natl Health Interview Survey? will not benchmark
comorbidities with this - too narrow
~~has~~ Westat has developed a tool

Pfizer
Dave - how funded? [20-30 min interviews]

Lennie - do see 100% funded

- want multiple companies / competing
some journals not accepting ins industry funded
make sure not barrier to public.

Don - we had talked re: broadening beyond pharma
eg, insurance w/state

Dave - do you envision some more willing to talk
Bill - minimize in training

~~APP~~ - may let more discussion @ end of survey

Portenoy - just did similar survey w/out letter
94 1/2 % response

ADRIENNE BRAUN - community advocate (Dana)
fall from swing @ 8 (arm/elbow injury)
swollen/blue - diagnosed w/TSB

TRENDS & BARRIERS - PORTENOV

operations vs meds

poor recommendations for interventions

disarray both w/in & w/out

- healthcare system / standards of care

- disjointed prof community in pain —
don't talk

protecting turf vs broader agenda

- fed gov / reg community

- population Δ - incl more diversity

little research incl basic pharm of
ethnic communities)

new research

eg, pain genetics

pain biol w/clin trials

↑ dialogue
w/ pain mgmt & fed gov

still local
disconnect

2 bills - probably never pass but good
role of pharma - partnerships w/academia
 ↓
 R&D - new molecules
 - new delivery systems

Will

2004 - 2005 →³ most signif challenges

[AAPM 70% docs -
proceduralists per Marsh]

ISSUES

put pain on political map
access to branded pharma
drug delivery / development → narrow now (reg)
educ regulatory bodies re need for pain mgmt
common terminology for pain mgmt
hesitancy to prescribe, take, reimb potent med
Δ in health care system - reimb / managed care / \$
pain on popular map
more evidence based treatment guidelines - HEORs
reimb for comprehensive pain mgmt care
finding a balance - reg / media / public / prof ed
 ↑ reg scrutiny
 addressing
fragmentation in pain societies

Access to appropriate [providers, prod/ reimb]

Prof Ed - starting in med school

Industry wants to help - can't help all

collaboration

Addressing LAO issues immediately

how to exploit decade of pain

political / consumer map similar

collaboration w/ focus - Michael

Marsha - APF vying for \$ w/ prof soc \$

also other orgs

terminology could help

Pam - key msgs - what are they

- what are audiences

Will - APF & consumer-based org - all pain

not disease focus

strong link to med/science community

Molly - NPF vs APF?

Lennie - time is now to define roles of orgs

what can we each do

- APF has had Wash representation - did organizing makes us stand apart from other orgs

other groups say APF just advocacy - not true

- also dedicated person for media - go to org for media

- also launched on the ground advocacy campaign @ state level

NACPI, ASPMN, ACS

~~Michael~~

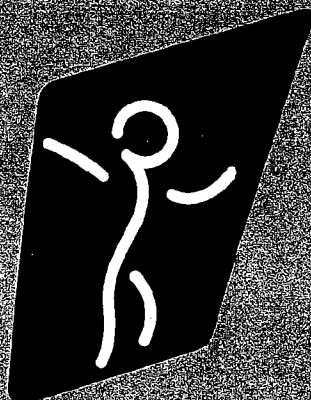
Coral - NPF Ambassador's Program

Michael - ^{Ligand} caused merger of 2 lymphoma orgs

Robin Hogen - APF has staff - take leadership

collab - need to coalesce a key msg

FINDING HELP FOR YOUR PAIN



A PAIN RESOURCE GUIDE
AMERICAN PAIN FOUNDATION



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FIND THE PAIN

If you are a person with serious chronic pain there's a good chance you've been going from one healthcare provider to another looking for relief. There's also a good chance you've heard the words, "Nothing more can be done to ease your pain" or "You'll just have to live with it."

This resource guide is designed to encourage you to take charge of your pain and to help you find a healthcare provider who has the know-how, skills, and willingness to work with you to manage it.

Know the facts: more than 50 million Americans—men, women, and children—live with serious chronic pain that interferes with their personal, social, and work lives. Although we now have the medical knowledge to manage most pain, most goes untreated, is undertreated, or is improperly treated.

CARE YOU NEED

Why is finding a healthcare provider who is knowledgeable and skilled in pain management so difficult? Because understanding that chronic pain is a disease in itself—and one that is harmful to the body—is a new way of thinking. Until recently, pain was considered only as a symptom of a disease or condition, or just a natural part of aging. So most healthcare providers have been trained in treating diseases—not pain.

Today, we know that pain should never be ignored. It should be assessed thoroughly and treated aggressively, and in some cases managed as a chronic condition. We've learned that when pain is managed, stress is reduced, and the body heals faster. We also know that when people with pain take an active role in their pain management, they get the best results possible: less pain and more involvement in life.

GOOD PAIN MANAGEMENT BEGINS WITH YOU!

Your goal is to manage your pain and not let it manage you.

- **Get a correct diagnosis.** Your pain may or may not be signaling a disease or infection in your body.
- **Be in charge. Speak up! Be your own best advocate.** Understand that your pain needs to be assessed and treated because it can be very harmful to your body. Tell your healthcare provider you are in pain. Don't let anyone tell you your pain is "just in your head."
- **Realize that you are the expert on your pain.** Neither your healthcare provider nor anyone else can know how much you are hurting, where you are hurting, and how pain is interfering with your life.
- **Make a personal commitment to reducing your pain.** Be persistent. Start with determination and a positive outlook. Participate actively in your pain care all along the way—from finding a healthcare provider to developing and sticking with a pain management plan.
- **Do your homework!** Become informed and learn all you can about your health problem, your pain, pain management options, and the types of healthcare providers who specialize in pain. Use the tools and resources you would use to learn about anything else. Start by using the American Pain Foundation's (APF) publications and website (www.painfoundation.org). You can also visit your local library, search the Internet, and talk to people you know who are living

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with pain. Reference librarians will often do Internet searches for you if you do not have a computer.

- **Learn to describe your pain symptoms clearly:** how much it hurts, where it hurts, how often it hurts, and what it feels like so you can contribute to the assessment of your pain. APF's pain assessment guide will help: www.painfoundation.org/page.asp?menu=1&item=3&file=documents/doc_036.htm

- **Ask your healthcare provider if he or she is comfortable helping you manage your pain, and working as your partner in developing a pain management plan.** Make sure your healthcare provider:

- Knows about chronic pain and how to treat it.
- Believes your report of pain.
- Listens carefully to your concerns.
- Asks you questions and performs diagnostic tests to identify the problem.
- Encourages you to ask questions.
- Is comfortable when you disagree.
- Is willing to speak to your family or friends if you are not feeling well.
- Works with you to develop a pain management plan, including risks and benefits of each treatment.
- Tells you when he or she does not know something about your pain problem or treatment.

LEARN ABOUT TREATMENT OPTIONS

There are many ways to treat pain. Find out about the benefits and risks of drug and non-drug therapies. Learn about the different ways drugs can be taken. For example, opioids—strong medications for relieving serious pain—can be delivered through pills, a transdermal patch, or a pump. Many non-drug therapies, used alone or in combination with medications, can also help reduce pain. A few include psychological counseling and physical therapy, as well as a host of complementary and alternative treatments such as massage, acupuncture, and yoga.

WHEN SHOULD I SEE A PAIN CARE SPECIALIST?

Your family healthcare professional is trained to know about a wide range of diseases, but may not have had much training in treating pain. If your current treatment is not working or if your pain is getting worse, it's probably time to see a pain specialist.

FIND A PAIN SPECIALIST

START ASKING, START CALLING

Start by asking your provider to refer you to a specialist with expertise in treating your particular problem. A good question to ask is, "Who would you go to if you were in pain?" If he or she cannot suggest a specialist, the next step would be to check with your health insurance provider to see if there are pain specialists or pain clinics in your plan. You can also look for pain specialists by:

- Asking friends, family members, co-workers—particularly those who've had pain or know someone with pain—for suggestions.
- Speaking with people who belong to pain support groups in your area or region. Ask what doctors they like and why. Ask them what they look for in a specialist or pain center. Check with the American Chronic Pain Association: ACPA@pacbell.net, www.theacpa.org, or 800-533-3231.
- Contacting the referral service of the largest hospital in your area.
- Calling state and county medical societies.
- Contacting your local chapter of the American Society of Pain Management Nurses (ASPMN), the American Pain Society (APS), and the American Academy of Pain Medicine (AAPM).
- Calling your local hospice. They can be helpful in finding a pain specialist even for non-end-of-life pain care. Also, someone in your State Cancer Pain Initiative may be able to suggest specialists even if your pain is caused by something other than cancer.

NO PAIN SPECIALISTS IN YOUR AREA?

- Call or write your chamber of commerce and/or contact the board of directors (chairman or members) of your local hospital. Ask about a larger hospital offering outreach clinics or visiting physicians.
- Contact your local legislators about the lack of resources and request their assistance.

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LIMITED OR NO HEALTH INSURANCE

- Contact your local hospital's social services department or your local health department.
- Contact Chronic Care Solutions, a nurse-run site focused on long-term care assistance: 2801 N. Glebe Road, Arlington, VA 22207, www.chroniccaresolutions.com.
- Contact The Center for Patient Advocacy: 800-846-7444, www.patientadvocacy.org.
- Contact the Patient Advocate Foundation: 800-532-5274.

MAKE A LIST

Write down the names of the providers you think might be right for you. Leave room next to each doctor's name for notes and appointment times.

CALL THE PAIN SPECIALISTS' OFFICES

Before contacting the doctor, talk with the office manager or a nurse at the practice. Begin by saying that you are looking for a doctor who can treat your pain. Describe your pain briefly. They will know about the types of cases the doctor handles.

Some questions to ask:

- Does the doctor treat my type of pain?
- Is he or she accepting new patients?
- How long will I have to wait to get an appointment?
- Will you accept my insurance?

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- Is there a charge for an initial interview with the doctor?
- Are nurses involved in the practice and are they available to talk with me?
- Who will see me in case of an emergency?

INTERVIEW THE DOCTORS

As a self-advocate, it's up to you or someone helping you to interview the doctors on your list and determine who best suits your needs—that includes selecting someone who not only has the skills to treat you, but someone who makes you feel comfortable as well. Before going into the interview have all your questions written down. The interview will probably be no longer than 20 minutes. Get to the office early so that you can observe how the office works and how patients are treated. Do staff members and patients appear to be comfortable? Also, check the surroundings. Is the office clean? Is there adequate privacy?

Begin your interview by telling the doctor about your symptoms and all the medications you're taking. Describe other treatments for pain you've had. This interview will give you insight into the doctor's willingness and ability to communicate with you.

Some questions to ask the doctor:

- Have you treated others with my type of pain?
- What types of treatments do you use to treat my type of pain (medications and other therapies)?

- How would you describe good pain management?
- What is your success rate in treating my type of pain?
- How much relief should I expect from treatments?
- What do you think of complementary and alternative approaches (such as acupuncture, massage, hypnosis, herbal remedies)?

Other questions to ask:

- Are you a member of a pain specialty organization?
- What was the most recent pain conference or seminar you've attended?
- Do you do any teaching?
- Do you participate actively in improving pain management on a local, regional, or national level? If so, how?

CHECK THE DOCTORS' CREDENTIALS

Once you've selected one or more doctors, check them out by contacting your state or county medical society, the American Board of Medical Specialties (www.abms.org), and the Specialty Licensing Board (www.abms.org/member.asp). You can also ask the doctor's office to supply his or her credentials concerning schooling and special training.

SCHEDULE YOUR APPOINTMENT AND GET PREPARED

Once you've scheduled your appointment, gather your previous medical records and deliver these by hand to the doctor's office before the visit to make sure they are there for the doctor to review.

When you go in for your visit:

- Give the doctor a written description of your medical history, including all treatments for pain.
- Give the doctor a list of all medications you are taking including prescriptions, over-the-counter medications, and herbal supplements. Report any allergies.
- Discuss with your doctor what you expect from your treatment.
- Describe your goals. Ask the doctor to work with you to develop a pain management plan.
- Ask the doctor for a complete assessment of your pain.
- After the first visit, determine how satisfied you were with the visit. Did the doctor take enough time to answer all of your questions? Did he or she take time to ask you questions?
- If you were not satisfied with this visit for any reason, interview other doctors until you've found the right one.

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RESOURCES

FIND A HEALTHCARE PROVIDER

- American Academy of Family Physicians
www.familydoctor.org
- American Academy of Nurse Practitioners
www.aanp.org 202-966-6414
- American Academy of Physician Assistants
www.aapa.org 703-836-2272
- American Board of Medical Specialties
www.abms.org 847-491-9091
- American Medical Association
www.ama-assn.org 312-464-5000
- Cancer Care
www.cancercare.org 800-813-4673
- Center for Patient Advocacy
www.patientadvocacy.org 703-748-0400
- Doctor Directory
www.doctordirectory.com 828-255-0012
- Federation of State Medical Boards (disciplinary history of physicians)
www.docinfo.org
- Federation of State Medical Boards (verify physician credentials)
www.fsmb.org 817-571-2949
- National Conference of Gerontological Nurse Practitioners
www.ncgnp.org 703-802-0088
- Nurse Practitioner Central
www.nurse.net/np 202-659-2190
- Yellow Pages
www.yellowpages.com

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FIND A PAIN SPECIALIST OR CENTER

- American Alliance of Cancer Pain Initiatives (find listings of state initiatives)
www.aacpi.org 608-265-4013
- American Academy of Pain Medicine
www.painmed.org 847-375-4731
- American Academy of Pain Management
www.aapainmanage.org 209-533-9744
- American Board of Pain Medicine
www.abpm.org 847-375-4726
- American Chronic Pain Association
www.theacpa.org 800-533-3231
- American Pain Society
www.ampainsoc.org 847-375-4715
- Cancer Care
www.cancercare.org 800-813-4673
- Case Management Resource Guide
www.cmrg.com 800-784-2332
- Commission on Accreditation of Rehabilitation Facilities
www.carf.org 520-325-1044
- Mayo Clinic Pain Management Center
www.mayoclinic.com/findinformation/conditioncenters
- National Hospice and Palliative Care Organization
www.nhpco.org 703-837-1500
- Pain.com
www.pain.com/painclinics/default.cfm

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GET BACK TO LIFE!

HAVE A CLEAR AND REALISTIC EXPECTATION of Relief

- Know that chronic pain tends not to disappear.
- Accept that you may always live with some degree of pain.
- Decide that you will do all you can to reduce your pain to a tolerable level.
- Commit to living life again.

NOTES

YOUR SUPPORT IS NEEDED!

The American Pain Foundation, an independent, nonprofit 501(c)(3) organization, depends on unrestricted contributions and grants from individuals, foundations, and corporations. We would appreciate your support. Please send your tax-deductible donation to: American Pain Foundation, 201 N. Charles St., Suite 710, Baltimore, MD 21201-4111.

Join Us

Help us build the pain movement and support for those with pain. It's free! Sign up to receive our newsletter, updates, legislative alerts, "information you can use," and more. Just complete and return this form.

Name _____

Address _____

City _____

State _____ Zip _____

Telephone _____ Fax _____

E-mail _____

☐ I am a Person with Pain

☐ Friend or Family Member

☐ Healthcare Professional

☐ Patient Advocate

☐ Member of the Media

☐ Corporate Representative

☐ Other

☐ I am interested in becoming a volunteer

Mail to: American Pain Foundation

201 N. Charles St., Suite 710

Baltimore, MD 21201-4111

Fax to: 410-385-1832

Email: info@painfoundation.org

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9/02

ABOUT THE AMERICAN PAIN FOUNDATION:

The American Pain Foundation is an independent, nonprofit organization serving people with pain through information, advocacy, and support. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research on pain, and advocating to remove barriers and increase access to effective pain management.

For more information, visit our website:
www.painfoundation.org. There you will find information about the causes of pain, different treatment options, ways to find trained specialists, peer support, and how to cope with pain. Our website also provides links to over 200 carefully selected websites on pain and related topics.

If you are unable to access the Internet and need more information, please write to us at

**American Pain Foundation
201 N. Charles St., Suite 710
Baltimore, MD 21201-4111**

To order this guide or for more information,
leave a message on our toll-free line at
1-888-615-PAIN(7245)

Or send an e-mail to
info@painfoundation.org



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READING This Could Help EASE YOUR PAIN

PAIN ACTION GUIDE

AMERICAN PAIN FOUNDATION



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HOW SERIOUS IS IT?

More than 70 million Americans suffer from chronic pain, and each year another 25 million experience acute pain from injuries or surgery. Although most pain can be greatly eased with proper pain management, most goes untreated, is under-treated, or is improperly treated. **No one should have to suffer needlessly when the knowledge and ability to manage most pain is available.**

Once your pain is under control, you'll be able to sleep better, focus on work, enjoy relationships with family and friends, and take part in social activities. Also, if your pain has been caused by an injury or surgery, your recovery may be faster.

THE PAIN PROBLEM?

Finding good pain care and taking control of your pain can be hard work. But the results are rewarding. Learn all you can about your pain and possible treatments. Work in partnership with your healthcare provider.

NEW PAIN CARE STANDARDS FOR HEALTHCARE FACILITIES

Most hospitals, nursing homes, and other healthcare facilities are now required to assess and treat pain. They are also required to inform patients about their right to effective pain care. These new pain management standards were set by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).

KNOW THE FACTS!

Your pain may or may not be signaling a disease or infection. Be sure to get a correct diagnosis.

Pain is not something you "just have to live with." Treatments are available to lessen most pain. Left untreated, pain can worsen other health problems, slow recovery, and interfere with healing. Get help right away. Don't let anyone tell you your pain is "just in your head."

Not all healthcare providers know how to treat pain. If your healthcare provider is unable to treat your pain effectively, ask him or her to refer you to a specialist. You may need to consider changing providers.

Pain medications rarely cause addiction. Morphine and similar pain medications, called opioids, can be highly effective for certain conditions. Unless you have a history of substance abuse, there is little risk of addiction when these medications are properly prescribed by a doctor and taken as directed. Physical dependence—which is not addiction—may occur and cause withdrawal symptoms if you stop taking these medications suddenly. You'll need to go off your medications gradually.

Most side effects from opioid pain medications can be managed. Nausea, drowsiness, itching, and most other side effects caused by morphine and similar opioid medications usually last only a few days. Constipation, the side effect that is most difficult to manage, can usually be relieved with laxatives, adequate fluid intake, and attention to diet.

If you act quickly when pain starts, you can often prevent it from getting worse. Take your medications when you first begin to experience pain. If your pain does get worse, talk with your healthcare provider. Your provider may safely prescribe higher doses or change the prescription. Non-drug therapies, such as relaxation training, can also help give you relief.



PAIN CARE BILL OF RIGHTS

AS A PERSON WITH PAIN, YOU HAVE THE RIGHT TO:

- Have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Be informed by your healthcare provider about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- Participate actively in decisions about how to manage your pain.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are the rights you should expect for your pain care.

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How Do I Talk with My HEALTHCARE PROVIDER About My Pain?

Speak up! Tell your healthcare provider that you're in pain. It's not a sign of weakness to talk about your pain.

Tell your healthcare provider where it hurts. Do you have pain in one place or several places? Does the pain seem to move around?

Describe how much your pain hurts. Use a scale from 0 to 10: zero means no pain at all and 10 means the worst pain you can imagine. Explain when your pain is the highest, lowest, and how it is right now.

Describe what makes your pain better or worse. Is the pain always there? Does it go away? Does it get worse when you move in certain ways? Do other things make it better or worse?

Describe what your pain feels like. Use specific words like sharp, stabbing, dull, aching, burning, shock-like, tingling, throbbing, deep, or pressing.

Explain how the pain affects your daily life. Can you sleep? Work? Exercise? Participate in social activities? Concentrate? How does it affect your mood?

Tell your healthcare provider about past treatments for pain. Have you taken prescription medication or had surgery? Tried massage? Applied heat or cold? Exercised? Taken over-the-counter medications or vitamin supplements? Explain.

Write down your questions for the doctor or nurse before an appointment. Take notes at your visit. If possible, bring along a family member or friend for support.

HOW CAN I GET THE BEST RESULTS POSSIBLE?

Ask questions, and speak up if treatment isn't working. Follow your pain management plan, ask questions, and speak up if you're not getting relief. Sometimes the plan needs to be changed. If necessary, seek other help. Be persistent.

Set goals. With your healthcare provider, set realistic goals for things you most want to do, such as sleeping, working, exercising, or enjoying sexual relations. Begin with the easiest goals first.

Work with your healthcare provider to develop a pain management plan. This might include a list of medications, when to take them, and possible side effects. It may include therapies other than medication, such as meditation. Make sure you understand the plan and carry it out fully. If you don't, you are less likely to get relief.

Keep a pain diary. Write about your level of pain at different times, how you're feeling, and what activities you can and cannot do. Keep a record of medications you're taking or any non-drug treatments. Bring the diary to your doctor visits.

Ask your healthcare provider about non-drug, non-surgical treatments. These could include relaxation therapy, exercise, massage, acupuncture, application of cold or heat, behavioral therapy, and other techniques.

Ask your healthcare provider about ways to relax and cope with pain. Your pain may feel worse if you are stressed, depressed, or anxious.

If you have questions or concerns, speak up. If you're worried about medications or other treatments, ask your healthcare provider. You have a right to know

how and why treatments work. The more you understand, the better you'll be able to participate in your plan.

If you're having surgery, ask your healthcare provider for a complete pain management plan beforehand. Don't wait until after surgery to ask about your pain care.

If you're a patient in a hospital or other facility and you're in pain, speak up. Ask a healthcare provider for help. If you don't get help right away, ask again. If you still don't get help, speak to a social worker or patient advocate. As of January 1, 2001, most hospitals and healthcare facilities are required to assess and treat your pain.

Pace yourself. Once you experience some degree of control over your pain, don't overdo it. Your body may be out of condition. Take time to gradually build up to normal activity.

If you're not satisfied with your pain care, don't give up. Does your healthcare provider listen to you? Is he or she able to assess and treat your pain? If after a reasonable time the answer is "no," ask for a referral to a pain specialist, or find another healthcare provider.

How Should My Pain Be Treated?

First, understand that your pain should be treated. Left untreated, pain can be harmful to your body. Pain treatments vary for different conditions. Ask your healthcare provider to tell you about treatment options that can help manage the pain that comes with your particular condition. In addition, find out about ways to reduce stress and cope effectively with your pain.

Most often, people with moderate to severe chronic pain (pain that persists over time) get the very best results

with a combination of therapies that address the physical, functional, emotional, and spiritual aspects of pain.

PAIN MEDICATIONS: Medications, called analgesics, are valuable tools for reducing pain. Pain medications work best if taken before the pain becomes severe. You should take these medications when you begin to feel uncomfortable. Once pain becomes severe, it takes more time and more medication to bring it under control.

All medications, both over-the-counter and prescription, can have side effects. That's why it's important to take medications as directed and let your healthcare provider know about all of the medications you are taking (see guidelines below).

Acetaminophen is a basic pain reliever that can be bought over-the-counter. Acetaminophen is often effective in managing mild pain. When taken as directed it is usually safe. If taken for an extended period, your healthcare provider should be aware and may want to monitor you for stomach, liver, and/or kidney problems. Acetaminophen comes as tablets and rectal suppositories.

Nonsteroidal anti-inflammatory drugs (NSAIDs) are pain relievers that are available over-the-counter (such as aspirin, ibuprofen, and naproxen sodium) and by prescription. NSAIDs are stronger than acetaminophen and are often used to treat mild to moderate pain. Cox-II inhibitors (such as rofecoxib and celecoxib) are new forms of NSAIDs. These drugs may be easier on the stomach and cause less bleeding problems than standard NSAIDs. However, they may not be safe for some people with heart disease or those allergic to sulfa. Most NSAIDs are available in pill form.

The drugs above are associated with liver damage, especially when used with alcohol or taken over a long period. NSAIDs can affect the kidneys and promote bleeding. They also have a "ceiling effect"—after the maximum dose is reached, there is no additional pain relief.

Opioids are strong medications used to relieve moderate to severe pain. Available only by prescription, opioids come in a variety of dosing forms and are sometimes combined with other substances such as aspirin and acetaminophen. Some opioids are given in pill form. Medications such as morphine and fentanyl can also be given through a transdermal skin patch (fentanyl only), injections into the veins or tissue, or under the skin into the muscle. Opioids can also be given under the tongue, through rectal suppositories, or in some cases, injected into the epidural or spinal space. **Short-acting oral opioids**, such as Oxycodone and hydromorphone, provide 4 to 6 hours of pain relief and are often used for breakthrough pain—short episodes in which pain increases dramatically. **Long-acting opioids** usually last longer (8 hours to 3 days), and are used for moderate to severe pain states, such as lower back pain, osteoarthritis, and cancer.

More information on opioids can be found on the APF website: www.painfoundation.org

OTHER PAIN MEDICATIONS: Some medications that were developed to treat other conditions (such as anti-depressants, anti-inflammatory steroids, and anticonvulsants) can be helpful for treating pain. They are often given in combination with other analgesics. Discuss any questions you have about these drugs with your health-care provider and your pharmacist.

Topical medicines (applied to skin), like creams that contain anesthetics (numbing medicine) or capsaicin (made from hot peppers), may relieve pain on the surface level.

NON-INVASIVE, NON-DRUG THERAPIES: There are many non-drug therapies for relieving pain. They can be used alone or in combination with drug therapies:

Thermal treatments, such as applying heat (heating pad) and/or cold (ice pack), can reduce pain by allowing "non-pain" sensations to overload the nervous system.

Professional therapeutic massage is a method of manipulating the soft tissues of the body to relieve pain, release tension, and restore function. Often, balms or lotions are used with massage to increase relief of pain that is caused by tension, spasms, or painful areas called "trigger points."

Physical therapy, which can help improve function and quality of life, often includes: manual therapy techniques; exercises to improve strength and balance; use of physical agents such as ultrasound or electrical stimulation; and functional training.

Chiropractic is a system of adjusting segments of the spine to remove nerve interference. Chiropractors may also use other therapies, such as lifestyle and nutrition counseling.

Psychological counseling/cognitive therapy offers people powerful skills to help them manage their pain and stress.

Mind/body techniques are based on the idea that the mind and body work together as a unit. Mind/body techniques can relieve pain by reducing stress (which helps the immune system). Mind/body techniques include biofeedback, hypnosis, yoga, guided imagery, prayer and meditation, and music and humor therapy. These therapies help disengage consciousness.

Acupuncture is one of the oldest therapies known to mankind, and involves the insertion of very fine metal needles into the skin at specially designated points of the body. Acupuncture is thought to work by altering the body's energy flow and allowing the body to regain its balance and heal itself.

INVASIVE PAIN THERAPIES: These are methods recommended for chronic or combined pain problems. Healthcare providers with special training in pain management can evaluate whether these methods could

improve your pain relief and give you information about what you can expect.

Analgesia catheters and infusion pumps deliver drugs such as opioids, anesthetics (numbing agents), and muscle relaxants. Catheters are placed in a variety of locations of the body. Sometimes they are used for a short period of time (for acute pain after surgery), or they can be surgically implanted for complex pain (cancer pain or nerve pain). An analgesia pump may be connected to the catheter and worn outside the body (short-term) or surgically placed inside the body (long-term). Special training is required for pain physicians and nurses offering these therapies.

Injection therapies may be used for pain located in a specific area of the body. Injecting medication to numb and stop inflammation may reduce the number of pain signals. These "nerve blocks" may give short or long-term relief, depending on the pain problem and your unique response. A physician requires special training to perform these injections.

Chemical, thermal, or surgical ablation may be used for some complex nerve pain problems. These methods destroy nerves that sense pain and other feelings (such as touch or pressure) without involving nerves used for movement and strength. Strong chemicals like phenol or alcohol may be used. Extreme temperatures from freezing (called cryoanalgesia) or heat (radiofrequency) may be recommended. Surgery may be used to either permanently cut the nerve area or remove the suspected cause of pain (spinal disc, tumor, etc.). For some people, surgery may provide complete and permanent relief, while for others the relief may be temporary or partial.

Spinal cord stimulators (SCS) or dorsal column stimulators (DCS) may be inserted for some special nerve pain problems. An electrode (metal wire) is placed around the spinal nerves that are receiving pain

messages. A small transmitter is programmed to send signals that block pain messages before they enter the spinal cord (where pain messages go before traveling to the brain for recognition). This transmitter can be worn on your clothing. Physicians who insert and manage this therapy require special training.

Radiation may be recommended if pain is caused by a tumor. This therapy helps to shrink the tumor size that may be pressing on nerves. Special radiation therapies may also be used to lessen bone pain.

Guidelines for Taking Medications

Tell your healthcare provider about all the medications you are taking—both prescription and over-the-counter. Include vitamins and herbal supplements. Medications and herbs can interact with each other and cause side effects or complications. In some cases, some combinations of medications can either reduce or increase the effects of other needed medications. For more information, see the National Council on Patient Information and Education (NCPIE) website at www.medsense.org.

Talk to your healthcare provider about any food or medication allergies you may have. This information can help determine your treatment.

Take all medications as directed. Even common, over-the-counter medications can have side effects—particularly if not taken as directed.

Talk to your pharmacist about your medications and how different foods might interfere with how they work.

Caution: alcohol, in combination with many pain medications, can be very dangerous. If you drink, even socially, let your healthcare provider know.

WHERE CAN I FIND HELP?

- Start at APF: www.painfoundation.org, toll-free 888-615-PAIN.

If you want to find a pain specialist:

- Ask your healthcare provider for a referral to a pain specialist or pain clinic.
- Ask family, friends, and co-workers who have had pain.
- Contact the referral service of the largest hospital in your area.
- Call your state and county medical societies.
- If you are in a managed care program, call your representative and get the list of approved pain specialists.
- Your local hospice can often suggest pain specialists.

Additional Resources

- American Alliance of Cancer Pain Initiatives www.aacpi.wisc.edu
608-265-4013
- American Academy of Pain Medicine www.painmed.org
847-375-473
- American Academy of Pain Management www.aapainmanage.org
209-533-9744
- American Board of Pain Medicine www.abpm.org
847-375-4726
- American Chronic Pain Association www.theacpa.org
800-533-3231
- American Pain Society www.ampainsoc.org
847-375-4715
- Cancer Care www.cancercare.org
800-813-4673
- Case Management Resource Guide www.cmrg.com
800-784-2332
- Mayo Clinic Pain Management Center www.mayoclinic.com
- National Hospice and Palliative Care Organization www.nhpco.org
703-837-1500
- Pain.com www.pain.com

To Find Support

- APF's PainAid painaid.painfoundation.org
- American Chronic Pain Association www.theacpa.org
916-632-0922

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YOUR SUPPORT is NEEDED!

The American Pain Foundation, an independent, nonprofit 501(c)(3) organization, depends on unrestricted contributions and grants from individuals, foundations, and corporations. We would appreciate your support. Please send your tax-deductible donation to: American Pain Foundation, 201 N. Charles St., Suite 710, Baltimore, MD 21201-4111.

Join Us

Help us build the pain movement and support those with pain. It's free! Sign up to receive our newsletter, e-newsletter, legislative alerts, and more. Just complete and return this form.

Name _____

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- ☐ I am a Person with Pain
☐ Friend or Family Member
☐ Healthcare Professional
☐ Patient Advocate
☐ Member of the Media
☐ Corporate Representative
☐ Other
☐ I am interested in becoming a volunteer

Mail to: American Pain Foundation
201 N. Charles St., Suite 710
Baltimore, MD 21201-4111
Fax to: 410-385-1832
Email: info@painfoundation.org

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ABOUT THE AMERICAN PAIN FOUNDATION

The American Pain Foundation is an independent, nonprofit organization serving people with pain through information, advocacy, and support. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research on pain, and advocating to remove barriers and increase access to effective pain management.

For more information, visit our website: www.painfoundation.org. There you will find information about the causes of pain, different treatment options, ways to find trained specialists, peer support, and how to cope with pain. Our website also links to over 200 carefully selected websites on pain and related topics.

If you are unable to access the Internet and need more information, please write to us at:

American Pain Foundation
201 N. Charles St., Suite 710
Baltimore, MD 21201-4111

To order this guide or for more information,
leave a message on our toll-free line at
1-888-615-PAIN (7246).

Or send an email to
info@painfoundation.org



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